

The eye care profile and outcomes of multi-handicapped adults residing in Wayne County, Michigan group homes

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Background: Patients with multi-handicaps present clinical challenges and are underserved. Central nervous system dysfunction and ocular disorders with this population are prevalent and well-documented. However, vision care outcomes data are limited and specific visual function recommendations to caregivers are rarely cited.

Methods: The charts of 110 multiply handicapped adults residing in 22 group homes in Wayne County, Michigan were retrospectively studied to identify ocular profiles and predictors of visual function.

Results: Sixty-five percent of the subjects were male and 80% were ages 26 to 55 years. There was no expressive language in 41%, and 37% were non-ambulatory. The median visual impairment level was moderate in both eyes (based on WHO). Significant associations between visual impairment level and subpopulations (such as seizure disorder, mental retardation without specific etiology, cerebral palsy, and Down syndrome) were identified. Successful spectacle wear statistically increased with higher refractive errors. Associations between cataract, nystagmus, and strabismus with particular subpopulations were significant (all *P* values < 0.0182).

Conclusions: Clinicians who evaluate patients with multi-handicaps have few known predictors of treatment success. This study indicates that useful predictors of visual function can be made from refractive error, systemic conditions, and ocular diagnoses. No significant relationship was found with cognitive level and either vision impairment or spectacle use. The authors attribute successful implementation of recommendations to communication with group home caregivers.

Key Words: Caregivers, developmentally disabled adults, disabilities, group homes, health care, mental retardation, multiply handicapped adults, outcomes, quality of life, refractive error, vision impairment, visual function

Advanced medical technology has allowed a significant number of premature infants, children with severe congenital impairments, and victims of acquired brain injury (ABI) to survive into adulthood. Their multiple disorders frequently involve the central nervous system (CNS), with associated vision impairment. Many have damage to the visual pathway, resulting in optic neuropathy, cortical visual impairment, strabismus, and nystagmus.¹⁻⁵

In February 2002, the Surgeon General reported that many Americans with mental retardation received inferior health care. The report targeted social stigma and shortcomings in insurance programs as part of the problem. It called for health care providers to meet this public health challenge through professional training, including taking the necessary time to modify examination techniques.⁶

The increasing numbers of patients with multi-handicaps all need eye care. This can be a challenge to the clinician in the primary care setting. The examination and determination of visual function level—referred to here as *functional vision assessment*—for developmentally and/or behaviorally disabled patients is far from a routine service. Optimal care of these patients often requires interactions with caregivers and other health care and social service disciplines.^{1,7-9} Limited studies are available to guide clinicians due to the complexity of individual medical histories, the availability of minimal subjective data, and the lack of established clinical profiles.^{2,10-12}

In recent years, more adult multihandicapped individuals reside in group homes than in large institutions.⁶ The existing eye care literature relating to those with multi-handi-

caps largely represents studies of children in special needs clinics and adults in larger institutions.^{2,4,7,8,11-19} Group homes offer unique environments to implement treatment plan recommendations and allow the evaluation of outcomes of that care. This smaller, more personable living arrangement permits consistency of familiar caregivers in a non-threatening environment, assistance with daily living activities, and sheltered workshops. Communication with caregivers as to the patients' visual function can play a critical role in maximizing treatment plan success.⁸ Caregivers can implement treatment recommendations to appropriately involve the patient in rehabilitation activities and promote a maximum level of independence in the least restrictive environment.⁸

Prevalent conditions of those with multi-handicaps include seizure disorders, mental retardation without specific etiology, ABI, cerebral palsy, and Down syndrome. Aggressive behavior, tactile defensiveness, poor visual attention, and poor motor control are often observed. Seizure disorders are common in this population, with the prevalence and severity of these disorders highest with premature births and developmental disorders.^{5,8} Mental retardation has been found in 13% of students with developmental disabilities, having varying degrees of presentation with no known etiology.^{5,8,20} The average best-corrected visual acuity of children with mental retardation is known to be 20/29.¹⁷

The incidence of cerebral palsy in the general population is 1 in every 1,000 births, and is present in 4.3% of the mental retardation population.^{4,12} Even with sometimes severe neurological impairments, those with cerebral palsy can survive past 60 years of age and can have average intelligence.⁴ Common ocular findings of those with cerebral palsy include hyperopia and an average visual acuity of 20/49, with up to 34% having visual acuity worse than 20/40.^{17,21,22} Down syndrome has an overall incidence of 1 in every 660 births.⁴ It is associated with mental, cardiac, and respiratory impairment, but generally less damage to the CNS than those with cerebral palsy or seizure disorder.^{4,7,23,24} Down syndrome comprises 16% to 17% of the mental retardation population and is associated with a shortened life span.^{4,12} Studies indicate that the common ocular disorders of Down syndrome are

myopia (at times high), cataract, nystagmus, and keratoconus.^{17,23,24} The average best-corrected visual acuity of those with Down syndrome is reported as 20/68 to 20/100.^{17,24}

Previous research has demonstrated success in spectacle compliance and the positive impact on the behavior of those with multiple handicaps.¹³ The correction of higher refractive errors has generally been more successful than lower corrections.^{2,13} To our knowledge, no studies have documented patterns of spectacle compliance based on specific refractive errors, and few reports include the clinical recommendations to caregivers or the importance of the caregiver understanding of functional vision recommendations.^{8,19}

The impact of clinical services on patient quality of life is becoming an important factor in guiding health care policy decisions.²⁵ The goals of this study were to identify clinically relevant trends as predictors of visual function outcomes and to document the statistical significance between specific disabilities and ocular disorders. Obtaining subjective-based data for outcomes studies (such as a quality of life measurement) is extremely difficult with this population due to the severity of cognitive and language impairments.

Methods

Subjects

The charts of 110 adults with multi-handicaps, evaluated between 1996 to 1998 at Low Vision Associates, P.C., in Bingham Farms, Michigan, were studied retrospectively. The subjects were selected by simple random sampling of 110 adult patients from a table of 230 patient numbers. All were ages 18 years or older, from one of 22 group homes, and—prior to this examination—either suspected of having a visual impairment or determined to be "unreliable" for vision testing. Most were severely-to-profoundly mentally impaired, as noted in the record, with developmental ages ranging from infancy to childhood (standardized developmental ages or IQ to describe mental impairment were not consistently available). Behavioral disorders included inattention, tactile defensiveness, and aggressive behaviors. Language impairment and lack of symbol recognition were also common clinical challenges.

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